A feeling of subjective health by patients with multiple sclerosis

(Odczuwania subiektywnego stanu zdrowia przez chorych na stwardnienie rozsiane)

K Czerwińska-Mazur [1,A,D], M Kulesa-Mrowiecka [1,F], Z Kopański [1,C,E], J Tabak [2,B,C], M Mazurek [2,B]

Abstract – Introduction. Multiple sclerosis is a chronic disease of the central nervous system. It may have a different dynamic course, however, as a rule, constant disease progression is noted. The disease may contain various symptoms of varying individual severity. The effectiveness of their treatment is determined by properly, individually selected pharmacological treatment affecting the natural course of the disease, symptomatic treatment, rehabilitation. High relevance of this topic has led authors to undertake their own research.

Aim of the study. To examine the feeling of the subjective state of patients' health with multiple sclerosis. Determining the perception of the importance of physical rehabilitation for this group of patients.

Materials and methods. 62 people participated in the study (36 women and 26 men) aged 20-69 with diagnosed and treated multiple sclerosis. At the time of the research, all patients were covered by an outpatient rehabilitation program. The research used the method of a diagnostic survey, and the applied research technique was the author's questionnaire.

Results and conclusions. 74.2% of patients with multiple sclerosis described their health condition as good or satisfactory. From 32.26 to 80.65% it was able to perform basic activities related to everyday life. The respondents most often (88.71%) pointed emotional disturbances accompanying their illness in a high degree, followed by disturbances of the bladder and intestinal functions, which were very strongly afflicted by 85.48% of the subjects, then hypersensitivity to heat, which in 82.26% of the respondents and muscle tone disorders - spasticity, which concerned in a very severe form 80.65% of patients, registered very severe symptoms. 75.81% of respondents thought that motor rehabilitation greatly improved their physical fitness, while a further 11.29% of respondents considered that only partially.

Key words **-** multiple sclerosis, pathological symptoms, physical rehabilitation, questionnaire survey.

Streszczenie – Wprowadzenie. Stwardnienie rozsiane jest przewlekłą choroba ośrodkowego układu nerwowego. Może mieć różnie dynamiczny przebieg, z reguły jednak odnotowywany się stały postęp choroby. W skład obrazu chorobowego mogą wchodzić różne objawy o różnym indywidualnym nasileniu. O skuteczności ich leczenia decyduje właściwie, indywidualnie dobrane leczenie farmakologiczne wpływające na naturalny przebieg choroby, leczenie objawowe, rehabilitacja. Duża aktualność tej tematyki skłoniła autorów do podjęcia badań własnych.

Cel pracy. Zbadanie odczuwania subiektywnego stanu zdrowia chorych na stwardnienie rozsiane. Określenie postrzegania znaczenia rehabilitacji ruchowej dla tej grupy chorych.

Materiał i metodyka. W badaniach uczestniczyło 62 osoby (36 kobiet i 26 mężczyzn) w wieku 20-69 lat z rozpoznanym i leczonym stwardnieniem rozsiane. W chwili prowadzonych badań wszyscy pacjenci objęci byli ambulatoryjnym programem rehabilitacji. W badaniach wykorzystano metodę sondażu diagnostycznego, a zastosowaną techniką badawczą był autorski kwestionariusz ankiety.

Wyniki i wnioski. 74,2% chorych na stwardnienie rozsiane swój stan zdrowia określało jako *dobry* lub *zadowalający.* Od 32,26 do 80,65% było *wstanie wykonać* podstawowe czynności związane z codziennym trybem życia. Badani chorzy najczęściej (88,71%) wskazywali *zaburzenia emocjonalne* towarzyszące w dużym nasileniu ich chorobie, następnie *zaburzenia funkcji pęcherza moczowego i jelit,* które bardzo silnie dokuczały 85,48% badanych, później *nadwrażliwość na ciepło,* co w stopniu bardzo nasilonym rejestrowało 82,26% ankietowanych i *zaburzenia napięcia mięśniowego- spastyczność,* które dotyczyło w bardzo nasilonej postaci 80,65% chorych. 75,81% badanych uważało, iż rehabilitacja ruchowa w dużym stopniu poprawia ich sprawność ruchowa, natomiast dalszych 11,29% badanych uznało, że tylko częściowo.

Słowa kluczowe **-** stwardnienie rozsiane, objawy chorobowe, rehabilitacja ruchowa, badanie ankietowe.

Author Affiliations:

1. Faculty of Health Sciences, Collegium Medicum, Jagiellonian University
2. Collegium Masoviense – College of Health Sciences, Żyrardów

Authors' contributions to the article:

A. The idea and the planning of the study
B. Gathering and listing data
C. The data analysis and interpretation
D. Writing the article
E. Critical review of the article
F. Final approval of the article

Correspondence to:

Prof. Zbigniew Kopański MD PhD, Faculty of Health Sciences, Collegium Medicum, Jagiellonian University, Piotra Michałowskiego 12 Str., PL- 31-126 Kraków, Poland, e-mail: zkopanski@o2.pl

Accepted for publication: November 30, 2018.

I. INTRODUCTION

Multiple sclerosis is a chronic disease of the central nervous system. A polycystic disease with an increasingly partial autoimmune background. In adults, most often in young people, it takes the form of a clinically isolated syndrome, however in most cases it develops in the form of relapses (exacerbations) and remissions. Unfortunately, it may have a differently dynamic course, but usually the progress of the disease is noticed. The disease image may include various symptoms of varying individual severity. The effectiveness of their treatment is determined by properly, individually selected pharmacological treatment affecting the natural course of the disease, symptomatic treatment, rehabilitation. [1-7] The high relevance of this thesis prompted the authors to undertake their own research.

The research was aimed at determining the perception of the subjective state of health of patients with multiple sclerosis. Determining the perception of the importance of physical rehabilitation for this group of patients.

II. MATERIALS AND METHODS

Materials

62 people participated in the study (36 women and 26 men) aged 20-69 with diagnosed and treated multiple sclerosis. At the time of the research, all patients were covered by an ambulatory rehabilitation program at the Specialist Hospital Ludwika Rydygiera in Krakow.

Methods

The research used the method of a diagnostic survey, and the applied research technique was the author's questionnaire. The form contained 20 questions, in which 16 were single-choice questions, 3 open-ended questions (one had to be answered independently) and one question required a scale-based choice. The research was carried out from June 1 to July 31, 2018. The research was voluntary and anonymous.

III. RESULTS

The distribution of answers to selected survey questions

Question: *Please specify the duration of your illness?*

Both women and men most often suffered from multiple sclerosis from 10 to 15 years (58.33% of women and 57.69% of men had such a history of disease). The test results are presented in Table 1.

Table 1. The distribution of the answer to the question: *Please specify the duration of your illness?*

Question: Please specify the duration of your illness?	**Sex**			
	Women		**Men**	
	Number	%	Number	%
Up to 9 years	9	25,00	7	26,92
10-15 years	21	58,33	15	57,69
Over 15 years	6	16,67	4	15,38

Question*: Please specify the overall state of your condition, your health condition?*

48.39% of respondents described their health as perfect, 25.81% - as good, and 48.39% found them satisfactory. The test results are presented in Table 2.

Table 2. The distribution of the answer to the question: *Please specify the overall state of your condition, your health condition?*

Question: *Please specify the overall state of your condition, your health condition?*	**Number**	**%**
Excellent	7	11,29
Good	16	25,81
Satisfactory	30	48,39
Unsatisfactory	9	14,52

Question: *Please specify the intensity of your symptoms listed below?*

The respondents most often (88.71%) indicated emotional disturbances accompanying their disease in large intensity, followed by disorders of the bladder and intestinal function, which were very similar to 85.48% of subjects, and later hypersensitivity to heat, which in a very severe way recorded 82.26% of respondents and muscle tone disorders - spasticity, which affected in a very severe form 80.65% of patients. The test results are presented in Table 3.

Table 3. The distribution of the answer to the question: *Please specify the intensity of your symptoms listed below?*

Question: *Please specify the intensity of your symptoms listed below?*	**Very intensified**		**Poorly intensified**		**No changes**	
	Number	%	Number	%	Number	%
Muscle tone disorders - spasticity	50	80,65	9	14,52	3	4,84
Problems with maintaining balance and coordination of movements	49	79,03	10	16,13	3	4,84
Tiredness	36	58,06	14	22,58	12	19,35
Vision disorders	30	48,39	19	30,65	13	20,97
Speech disorders	38	61,29	15	24,19	9	14,52
Disorders of the function of the bladder and intestines	53	85,48	5	8,06	4	6,45
Hypersensitivity to heat	51	82,26	7	11,29	4	6,45
Emotional disorders	55	88,71	4	6,45	3	4,84

Question: *Is your health limited by any of these activities (please fill in the tables to answer specific questions?)*

Among the respondents 32.26 to 80.65% were able to perform the analyzed activities related to everyday life. At the same time, 9.68 to 19.35% had quite limited capacity to perform the activities mentioned in this question. The greatest difficulties would make the participants participate in running or in sports requiring high physical effort. None of the respondents made such attempts. The test results are presented in Table 4.

Table 4. The distribution of the answer to the question: *Is your health limited by any of these activities*

Question: *Is your health limited by any of these activities (please fill in the tables to answer specific questions?)*	**I have quite limited possibilities**		**I have limited possibilities**		**I am able to do it**	
	Number	%	Number	%	Number	%
Running, participation in sports that require a lot of commitment	-	-	-	-	--	
Moderately difficult tasks: cleaning, cooking	6	9,68	24	38,71	32	51,61
Bath, dressing up	12	19,35	30	48,39	36	58,06
Walking up a several flights of stairs	12	19,35	30	48,39	36	58,06
Walking up one flight of stairs	6	9,68	20	32,26	36	58,06
Walk more than 1 km	5	8,06	20	32,26	37	59,68
Walk more than 500m	10	16,13	32	51,61	20	32,26
Walk more than 100 m	6	9,68	6	9,68	50	80,65

Question: *Does rehabilitation have a positive effect on your emotional state?*

91.94% are of the opinion that physical rehabilitation builds a positive emotional attitude of the disease. The test results are presented in Table 5.

Table 5. The distribution of the answer to the question: *Does rehabilitation have a positive effect on your emotional state?*

Question: *Does rehabilitation have a positive effect on your emotional state?*	**Number**	**%**
Yes	57	91,94
No	2	3,23
I don't know	3	4,84

Question: *Does rehabilitation have a positive effect on your contact with the environment (family, friends, friends)?*

90.32% are of the opinion that physical rehabilitation has a positive effect on building a relationship with the patient's environment. The test results are presented in Table 6.

Table 6. The distribution of the answer to the question: *Does rehabilitation have a positive effect on your contact with the environment*

Question: *Does rehabilitation have a positive effect on your contact with the environment (family, friends, friends)?*	**Number**	**%**
Yes	56	90,32
No	2	3,23
I don't know	4	6,45

Question: *Does physiotherapy have a positive effect on the quality of life?*

87.10% are of the opinion that the physiotherapist's help improves the comfort of life and increases that comfort. The test results are presented in Table 7.

Table 7. The distribution of the answer to the question: *Does physiotherapy have a positive effect on the quality of life?*

Question: *Does physiotherapy have a positive effect on the quality of life?*	**Number**	**%**
Yes	54	87,10
No	1	1,61
I don't know	7	11,29

Question: *How do you assess your physical fitness during the period of using forms of rehabilitation?*

75.81% think that motor rehabilitation greatly improves their mobility, with a further 11.29% noticing a partial improvement in fitness. The test results are presented in Table 8.

Table 8. The distribution of the answer to the question: *How do you assess your physical fitness during the period of using forms of rehabilitation?*

Question: *How do you assess your physical fitness during the period of using forms of rehabilitation?*	**Number**	**%**
Much better	47	75,81
A little better	7	11,29
Similarly	6	9,68
A bit worse	2	3,23

Question: *Please, assess your possibilities of functioning during the remission period (withdrawal of symptoms)?*

87.10% evaluate the possibility of their functioning in the remission period negatively, while further 12.9% positively or moderately. The test results are presented in Table 9.

Table 9. The distribution of the answer to the question: *Please, assess your possibilities of functioning during the remission period (withdrawal of symptoms)?*

Question: *Please, assess your possibilities of functioning during the remission period (withdrawal of symptoms)?*	**Number**	**%**
Positively	6	9,68
Moderately	2	3,23
Negatively	54	87,10

Question: *Do you willingly accept help from other people?*

69.35% willingly accept help from other people, however 14.52% of patients feel self-conscious when someone helps them, while 11.29% - does not require help from other people. The test results are presented in Table 10.

Table 10. The distribution of the answer to the question: *Do you willingly accept help from other people?*

Question: *Do you willingly accept help from other people?*	**Number**	**%**
Yes, willingly	43	69,35
Yes, because I can't do it alone	3	4,84
I fell inhibited when someone helps me	9	14,52
I don't need help	7	11,29

Question: *Do you use the rehabilitation services of the National Health Fund?*

61.29% of respondents use motor rehabilitation proposed by the NFZ. The test results are presented in Table 11.

Table 11. The distribution of the answer to the question: *Do you use the rehabilitation services of the National Health Fund?*

Question: *Do you use the rehabilitation services of the National Health Fund?*	**Number**	**%**
Yes	38	61,29
No	24	38,71

Question*: Do you think that the frequency of rehabilitation granted by the National Health Fund is sufficient?*

38.71% of respondents are of the opinion that the frequency of rehabilitation granted by the National Health Fund for a patient with multiple sclerosis is sufficient, 19.35% of the respondents are of the opposite opinion. The test results are presented in Table 12.

Table 12. The distribution of the answer to the question: *Do you think that the rehabilitation frequency granted by the National Health Fund is sufficient?*

Question*: Do you think that the frequency of rehabilitation granted by the National Health Fund is sufficient?*	**Number**	**%**
Yes	24	38,71
No	12	19,35
I have no opinion	26	41,94

IV. DISCUSSION

Among the analyzed patients with multiple sclerosis, the largest group were people suffering from multiple sclerosis from 10 to 15 years. This relatively long duration of the disease allows us to think that they have a clear distance to their ailments and can assess their health with a high degree of insight. It is convinced by the observations of some authors [8,9]

Our findings indicate that 74.2% of respondents described their health condition as good or satisfactory (48.39% satisfactory). However, when the analysis of individual organ discomforts / dysfunctions that may accompany multiple sclerosis is made, the picture is not as optimistic as the opinions expressed earlier.

Our findings indicate that among the respondents 32.26 to 80.65% were able to perform basic activities related to everyday life. At the same time, from 9.68 to 19.35% had quite limited possibilities to perform the activities mentioned in this question. The greatest difficulties would make the participants participating in running or in sports requiring high physical effort. None of the respondents made such attempts.

Multiple sclerosis may be accompanied by a wide range of symptoms and ailments. The patients we examined most often (88.71%) indicated emotional disturbances accompanying their illness intensively, followed by disorders of the bladder and intestinal function, which were very strongly afflicted by 85.48% of subjects, and later hypersensitivity to heat, which in 82.26% of respondents and muscle tone disorders - spasticity, which in a very severe form were reported by 80.65% of patients, recorded very intense symptoms.

In our research, attention was also paid to the importance of physical rehabilitation for patients with multiple sclerosis. Our research showed that 91.94% of respondents believe that physical rehabilitation builds a positive

emotional attitude. A similar effect of rehabilitation is noted by Kowalik [10].

Our research shows that it also improves the way of communication and building the patient's treatment with the environment. 90.32% of respondents were of this opinion. 87.10% were convinced that the physiotherapist's help improves the comfort of the patient's life and an overall comfort.

A very important observation is the fact that 75.81% of respondents believe that motor rehabilitation greatly improves their mobility, while a further 11.29% of respondents considered that they only partially improved their efficiency.

It is especially important in the remission period, because in the period of alleviation of the course of the disease, as much as 87.10% evaluate the possibility of its functioning negatively. Both the remission period, but also the high level of disease symptoms forces patients to use the help of the second person. Our research shows that 69.35% of patients gladly accept help from other people, however 14.52% of patients feel self-conscious when someone helps them, while 11.29% - does not require help from other people.

It is widely emphasized that motor rehabilitation is an important part of the treatment of a patient with multiple sclerosis. [11-16]

Kowalik in his research evaluating the impact of rehabilitation on the quality of life of patients with multiple sclerosis indicates that rehabilitation improves functioning, reduces pain, improves cognitive functions, moves the patient away from his condition. The author noted a statistically significant improvement in the condition of the patients to compare the period before and after rehabilitation. [10]

The patients examined by us are also convinced about the positive role of rehabilitation in the treatment of patients with multiple sclerosis. It is probably due to this fact that 61.29% of respondents use motor rehabilitation proposed by the NFZ. At the same time, 38.71% of respondents believe that the frequency of rehabilitation granted by the National Health Fund for a patient with multiple sclerosis is sufficient, however 19.35% of respondents are of the opposite opinion

V. CONCLUSIONS

- 74.2% of MS patients described their health condition as good or satisfactory
- From 32.26 to 80.65% were able to perform basic activities related to day-to-day lifestyle.
- The patients we examined most often (88.71%) indicated emotional disturbances that significantly increased their illness, followed by abnormalities of the bladder and bowel function, which were very strongly afflicted by 85.48% of subjects, and later hypersensitivity to heat, what to a very severe extent was recorded by 82.26% of the respondents and disorders of muscle tone - spasticity, which concerned in a very severe form 80.65% of patients.
- 75.81% of respondents believed that physical rehabilitation greatly improved their physical fitness, while a further 11.29% of respondents considered that only partially.

VI. REFERENCES

[1] Antczak A, Baranowska-Bik A, Bartosik-Psujek H, Białecka M, Bik W, Członkowska A, *i wsp.* Neurologia. Warszawa; Medical Tribune, 2015.

[2] Barcikowska A, Biernat W, Bilikiewicz A, Bratosiewicz-Wąsik J, Dąmbska M, *i wsp.* Choroby układu nerwowego. Warszawa; Wydawnictwo Lekarskie PZWL, 2004.

[3] Barcikowska M, Członkowska A, Domitrz A, Drac H, Dziedzic T, Hausmanowa- Petrusewicz I, *i wsp.* Neurologia. Tom 2. Warszawa; Wydawnictwo Lekarskie PZWL, Warszawa 2014.

[4] Ebers G. Environmental Factors in Multiple Sclerosis. Lancet Neural 2008; 7(3): 268277- 25.

[5] Goodin DS. The epidemiology of multiple sclerosis: insights to disease pathogenesis. Hand Clin Neurol 2014;122:231-66.

[6] Disanto G, Morahan JM, Ramagopalan SV. Multiple sclerosis: risk factors and their interactions. CNS Neurol Disord Drug Targets 2012;11(5):545-55.

[7] Sawcer S, Franklin R, Ban M. Multiple sclerosis genetics. The Lancet Neurology 2014;13,7:700-709.

[8] Everly GS, Lating JM. A clinical guide to the treatment of the human stress response. New York; Kluwer Academic / Plenum Publishers, 2002.

[9] Gunnar MR, Vazquez D. Stress neurobiology and developmental psychopathology. W: Cicchetti D, Cohen D. Developmental Psychopathology: Developmental Neuroscience. Tom 2. New York; Wiley, 2006: 533–577.

[10] Kowalik J. Niesprawność ruchowa, a jakość życia chorych na stwardnienie rozsiane poddanych rehabilitacji. Probl Hig Epidemiol 2012; 93(2): 334-340.

[11] Polman Ch H, Thompson A J, Bowling A C, Noseworthy H J. Stwardnienie rozsiane. Przewodnik po lekach i leczeniu. Warszawa; Polskie Towarzystwo Stwardnienia Rozsianego, 2007.

[12] Schulz KH, Gold S M, Witte J. Impact of aerobic training on immune-endocrine parameters, neurotrophic factors, quality of life and coordinative function in multiple sclerosis. J Neurol *Sci* 2004; 225: 1–18.

[13] Gehlsen G M, Grigsby S A, Winant D M. Effects of an aquatic fitness program on the muscle strength and endurance of patients with multiple sclerosis. Phys Ther 1984; 64: 653–7.
[14] Mostert S, Kesselring J. Effects of a short-term exercise training program on aerobic fitness, fatigue, health perception and activity level of subjects with multiple sclerosis. Mult Scler 2002; 8: 161–168.
[15] Cendrowki W, Kwolek A, Wieliczko E. Rehabilitacja chorych na stwardnienie rozsiane. Mag Med 1997;2: 49–50.
[16] Cendrowski W, Kwolek A, Chemiel A, Siwik P, Regulski G. Wieloośrodkowe badania nad rehabilitacją ruchową chorych na stwardnienie rozsiane. Terapia 1997; 7: 6–8.